

Hidradenitis suppurativa through the lens of YouTube: a cross-sectional analysis

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To the Editor: Patients are increasingly utilizing social media platforms to find and share information regarding their health.^{1,2} Investigating health-related information uploaded by patients onto social media may offer unique insights into patient perspectives. YouTube, a popular video sharing platform, has already been used to study a wide variety of dermatologic diseases.³ However, to date, there are no studies describing the content of hidradenitis suppurativa (HS)-related videos on YouTube.

In this cross-sectional study, we analyzed 284 YouTube videos uploaded between 01/01/2016-11/21/2019 relating to “hidradenitis,” “hidradenitis suppurativa,” or “acne inversa” to investigate patient attitudes towards HS. Video content was manually classified by user type (i.e. who appeared in the video), predominant topics, and patient disease experiences, treatments mentioned, and treatment satisfaction, which was assessed using Fisher’s exact test). Two authors independently coded the videos with high interrater reliability (Cohen’s Kappa > 0.8).

The majority of videos featured patients (62.3%, 177/284) (**Table 1**). There was comparatively less participation by healthcare providers (21.1%, 60/284). Specifically, dermatologists were in the minority (7.0%, 20/284). Primary care physicians, surgeons, and naturopathic providers were also featured. Videos starring healthcare providers attracted the most views (**Supplemental Figure 1**), suggesting that audiences who are searching for HS-related videos are preferentially viewing content from healthcare providers.

Predominant topics included disease education (70.1%, 199/284), personal experiences (60.6%, 172/284), seeking community (28.5%, 81/284), advertisements (25.0%, 71/284), and inspirational videos (9.5%, 27/284). Citing the lack of education about HS and feelings of social isolation, the majority of patients referred to the YouTube HS community as an important resource for exchanging information about HS and finding psychosocial support.

Our study also revealed that delays in diagnosis were a significant problem for HS patients (28.8%, 51/177), which was attributed to feelings of isolation, embarrassment, and initial misdiagnosis by non-dermatologists. HS was usually mistaken for cancer, sexually transmitted diseases, or poor hygiene, causing significant and unnecessary distress.

Additionally, nearly three-quarters of patients stressed the impact of uncontrolled pain on quality of life (72.5%, 124/171). Therefore, a greater emphasis on pain management for HS patients is needed, as formal studies investigating pain management for HS are lacking.^{4,5}

Regarding treatment options, alternative therapies were the most frequently mentioned overall (**Supplemental Table 1**) whereas videos discussing surgery garnered the highest amount of views (**Supplemental Figure 2**). Of 107 videos that addressed treatment outcomes, 30% (32/107) and 70% (75/107) reported satisfaction and dissatisfaction, respectively. Patients reported higher satisfaction with nonconventional therapies (**Supplemental Table 2**) compared to conventional therapies (84.2% vs. 50.0%, $p=0.005$) (**Table 2**).

In conclusion, YouTube is a valuable data source for investigating HS patient perspectives and reveals potential unmet needs expressed by HS patients including deficiencies in patient education, paucity of psychosocial support, delays to diagnosis, inadequate pain control, and treatment dissatisfaction. The fact that social media has become a key source of information from which patients make health-related decisions in conjunction with the relative shortage of reputable sources of medical information on YouTube highlight the need for dermatologists to expand their online presence to improve patient outreach.

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Table Legend

Table 1. Hidradenitis Suppurativa Video Characteristics

^a Percentage out of 177 total videos featuring patients

I&D, incision and drainage; OCPs, oral contraceptive pills

Table 2: Comparison of Treatment Satisfaction with Nonconventional Versus Conventional Therapies

^a Lifestyle modification, alternative therapy

^b Antibiotics, steroids, biologics, phototherapy, laser, surgery, hormone therapy, spironolactone

^c Of 107 videos that addressed treatment outcomes, 43 videos that mentioned treatment satisfaction with both “conventional” and “nonconventional” treatment methods were omitted in this analysis that included 64 videos in order to better isolate if one method had a higher proportion of satisfaction than the other.

Mendeley Supplemental Table 1. Treatments Mentioned by User Type

^a Percentage out of 544 total treatments mentioned by all groups combined

^b Percentage out of 341 total treatments mentioned by patients

^c Percentage out of 75 total treatments mentioned by physicians

^d Percentage out of 36 total treatments mentioned by non-physician providers

Link: <https://data.mendeley.com/datasets/jmjzr2zhyx/1>

Mendeley Supplemental Table 2. Nonconventional Therapies

^a Also described as an oral treatment

Link: <https://data.mendeley.com/datasets/jmjzr2zhyx/1>

Table 1. Hidradenitis Suppurativa Video Characteristics

Video Features	(N, percent)
Patient	177 (62.3)
Healthcare Provider: Physician	36 (12.7)
Healthcare Provider: Non-Physician	19 (6.7)
Healthcare Provider: Medical Group/Foundation	5 (1.7)
News Company	1 (0.3)
Pharmaceutical Company	7 (2.5)
Advertisement/Commercial Company	33 (11.6)
Other	31 (10.9)
Disease Status^a	(N, percent)
Flaring	77 (43.5)
Stable	57 (32.2)
Not Mentioned	43 (24.3)
Predominant Topics	(N, percent)
Education/HS Awareness	199 (70.1)
Advertisement	71 (25)
Personal Experience	172 (60.6)
Seeking Community	81 (28.5)
Inspirational Video	27 (9.5)
Video Mentions Pain	(N, percent)
Yes	171 (60.2)
No	113 (39.8)

Provider Seen^a	(N, percent)
Dermatologist	32 (18.1)
Primary Care Provider	18 (10.2)
General Surgeon	13 (7.3)
Plastic Surgeon	16 (9.0)
Emergency Department/Inpatient Hospital Stay	12 (6.8)
Gynecologist	6 (3.4)
Unspecified Provider	41 (23.2)
Not Mentioned	73 (41.2)
Delay to Diagnosis^a	(N, percent)
Yes	51 (28.8)
No	5 (2.8)
Not Mentioned	121 (68.4)
^a Percentage out of 177 total videos featuring patients I&D, incision and drainage; OCPs, oral contraceptive pills	

Table 2: Comparison of Treatment Satisfaction with Nonconventional Versus Conventional Therapies

Fisher's Exact Test <i>P</i> -Value = 0.005	Dissatisfied, N (%)	Satisfied, N (%)
Nonconventional Therapy ^a	6 (15.8%) ^c	32 (84.2%) ^c
Conventional Therapy ^b	13 (50.0%) ^c	13 (50.0%) ^c
^a Lifestyle modification, alternative therapy ^b Antibiotics, steroids, biologics, phototherapy, laser, surgery, hormone therapy, spironolactone ^c Of 107 videos that addressed treatment outcomes, 43 videos that mentioned treatment satisfaction with both “conventional” and “nonconventional” treatment methods were omitted in this analysis that included 64 videos in order to better isolate if one method had a higher proportion of satisfaction than the other.		

Figure Legends:

Mendeley Supplemental Figure 1. Hidradenitis Suppurativa. Breakdown of the Number of Videos and Average Views by User Type

Link: <https://data.mendeley.com/datasets/jmjzr2zhyx/1>

Mendeley Supplemental Figure 2. Hidradenitis Suppurativa. Treatment Types Mentioned Based on Total Video Views

Link: <https://data.mendeley.com/datasets/jmjzr2zhyx/1>